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ABSTRACT

This newsletter feature issue focuses on services for persons with developmental disabilities that support the whole person by acknowledging, respecting, and incorporating aspects of identity such as race, ethnicity, religion, sexual orientation, gender, age, and class. Articles include: (1) "Serving the Whole Person: The Journey to Embracing Diversity" (Bonnie Shoultz and Marijo McBride); (2) "Supporting Diversity: What Will It Take?" (Betty T. Horton); (3) "The Need To Reconfigure Our Hard Drives" (James L. Mason and others), which describes the need to change attitudes and become culturally competent; (4) "Forging Coalitions" (John W. McClain and James E. Van Arsdall), which provides strategies for integrating the issues of minorities with disabilities into the national agenda of traditional civil rights organizations; (5) "Finding Support in a New Land" (Dao Xiong), which describes a parent outreach program for refugee families; (6) "Family Support in Inner-City Atlanta" (Lesa Nitcy Hope and Mary Yoder); (7) "Honoring Diversity through Spirit and Faith" (Bill Gavental); (8) "Is It Okay for Me To Love?" (Dave Hingsburger), which describes a program that provides sex education resources for individuals with developmental disabilities; (9) "Empowering Families To Manage Service" (Marijo McBride); (10) "Seeing the Wheel within the Wheel" (Early Schwartz), which describes an educational program for Jewish individuals with developmental disabilities; (11) "Making Inclusion a Reality" (Ella Gross), which describes a program that promotes community inclusion for African American individuals with developmental disabilities; (12) "Serving Children and Families Who Are Homeless" (Tawara D. Taylor and others); and (13) "Improving Outreach to American Indians" (Priscilla Sanderson). Stories of individuals with developmental disabilities who have taken part in the described programs are included. A list of eight resource publications is also provided. (CR)

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IMPACT

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COMMUNITY INTEGRATION
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Feature Issue on Supporting Diversity **Volume 9 (3) Summer 1996**

The stories of the individuals pictured above, shared in this *IMPACT*, reveal the importance of providing services for persons with disabilities in a manner that respects and supports the rich personal and cultural heritage of each person.

From the Editors

The focus of this issue of *IMPACT* is on services for persons with developmental disabilities that support the whole person by acknowledging, respecting, and incorporating aspects of identity such as race, ethnicity, religion, sexual orientation, gender, age, and class. This issue is about learning from people how to best serve them, rather than making assumptions about what they need or expecting them to fit into a certain system or model. It is about asking tough questions regarding the best ways to meet the needs of culturally diverse persons with developmental disabilities and their families, and being willing to hear a variety of answers, some of which are critical of the ways things are currently done. It is about the role of cultural communities in meeting the needs of persons with disabilities. And it is about the successes being experienced in innovative programs across the country.

In this *IMPACT*, most readers will find something that will affirm and articulate some aspect of their experience, and something that will challenge them and perhaps even evoke some defensiveness. We hope that, in the end, these articles will have raised awareness, informed about promising practices, and encouraged creativity and an expanded vision for services that meet the complex needs of very diverse, whole people.

Serving the Whole Person: The Journey to Embracing Diversity

by Bonnie Shoultz and Marijo McBride

Most providers of services for persons with developmental disabilities realize that there is more to the individuals they serve than their disabilities. High quality agencies and programs try to see each person in some sort of broader context, taking into account characteristics ranging from family history to social networks to life dreams. Where things can get uncomfortable, however, is in those situations in which we, as persons providing services and supports, encounter those aspects of identity that we don't understand, value, see as relevant, or have within our life experience. It is at this intersection – at the place where service providers encounter not only the disability-related service needs of individuals, but also their race, ethnicity, gender, sexual orientation, religion, age, and socioeconomic class – that we find some of our strongest defensive reactions and our greatest challenges.

There are people who question the use of concepts such as race, gender, class, and the like. They point out that these categories are socially constructed, that is, created by our society and then acted upon and regarded as real. They would suggest that we should attempt to move

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A publication of the Institute on Community Integration (UAP) and the Research and Training Center on Residential Services and Community Living, College of Education and Human Development, University of Minnesota. Dedicated to improving community services and social supports for persons with disabilities and their families.

Supporting Diversity: What Will It Take?

by Betty T. Horton

I am saddened by the notion that "systems change" for persons with disabilities involves creating opportunities to exercise such commonly accepted freedoms as living in a home of one's choosing, holding a job, making decisions about all aspects of one's life, and speaking up for oneself. These are seen as the birthright of Americans, primarily associated with achieving adult status and fulfilling adult roles and responsibilities. Yet, it requires "systems change" to make these rights accessible to persons with developmental disabilities. And among those for whom such rights continue to be least accessible are persons with developmental disabilities who are African American, Hispanic/Latino, Native American or Asian American.

How long will it take before persons with disabilities are granted the full rights and responsibilities of citizenship? What will it take to fully heed the declaration of *Brown v. The Topeka Board of Education* that separate is not equal? And what will it take to improve the ability of programs and services for persons with developmental disabilities to represent and support diversity?

This article examines three stages of change in the realization of full inclusion for persons with developmental disabilities who have diverse cultural backgrounds and characteristics. The first stage is legal or legislative change that involves major Supreme Court decisions and federal mandates impacting the civil rights of persons with disabilities. The second stage is bureaucratic implementation, which addresses policies and procedures for service delivery. And the third stage is systems change, in which common sense attitudes and practices for supporting all persons with disabilities are implemented. These three stages will be explored and serve as the basis for a broad set of principles for providing holistic services that support diversity.

■ Stage 1: Two Landmark Court Decisions

This year marks the 100th anniversary of the Supreme Court ruling in *Plessy v. Ferguson* (1896) and the 42nd anniversary of *Brown v. The Topeka Board of Education* (1954). These cases form a crucial backdrop for the civil rights of persons with disabilities. Understanding the significance of these two landmark decisions is critical to an understanding of the current crossroads the United States is at regarding how we respect the rights of and provide services and supports for persons with developmental disabilities from diverse cultural backgrounds.

In the *Plessy* decision on May 18, 1896, the Supreme Court of the United States voted to sanction "separate but equal" public facilities for whites and blacks. For the next half-century, the law of the land was apartheid. On May 17, 1954, *Plessy* was overturned in an unanimous decision by the Supreme Court in *Brown v. The Topeka Board of Education*. The court ruled that separate was not equal and declared that racially segregated schools were inherently unequal.

Brown is a legal foundation for several important pieces of federal legislation upholding the civil rights of persons with disabilities. The first of these, Section 504 of the Rehabilitation Act of 1973, is regarded as landmark civil rights legislation. It requires that any program or activity receiving federal funds provide persons with disabilities, to the maximum extent possible, the opportunity to be fully integrated into that program or activity. Another legislative watershed was the Education of All Handicapped Children Act of 1975, now known as the Individuals with Disabilities Education Act (IDEA). This legislative mandate guarantees a free and appropriate public education to all children with disabilities. Fifteen years later, the Americans with Disabilities Act of 1990 extended the nondiscrimination mandate found in Section 504 and applied it more broadly to include all public or private employment, transportation, accommodations, and telecommunications regardless of whether federal funding is received. Additional policy goals in the Developmental Disabilities and Bill of Rights Act, the creation of the Medicaid Home and Community-Based Services waiver program, and supported work policies in amendments to the Rehabilitation Act have been designed to provide services and advocacy to support the rights of persons with disabilities.

■ Stage 2: Administrative Service Models

Taken together, legal and legislative mandates set the stage for changes in service delivery models. Changes in the philosophy and models for service delivery have been slow and arduous. Vestiges of the long history of segregation and fear of persons with developmental disabilities still remain today. It is ironic that although the *Brown* decision marked the end of the legal sanctions for unequal treatment by race and later by disability, these legal changes have not been reflected in service delivery models. Persons with disabilities from poor or racially diverse backgrounds have been over-represented in special education programs and prisons, and under-represented in vocational rehabilitation services, employment programs, and post-secondary education.

The assumption of "equitable distribution of services", regarded as the cornerstone of public policy in the provision of human services, has clearly not been met for some persons with developmental disabilities. For example, in studying why African Americans, Native Americans, Asian Americans, and Hispanic/Latino persons do not use vocational

rehabilitation services, several viewpoints are found to exist in the service system that undermine equity in this and other types of human services (Wilson, 1986; Hollins, 1982):

- **Deprivation Viewpoint: Blaming the Victim.** Some service providers regard persons with developmental disabilities and their families who are from diverse cultural communities as hard-to-reach or difficult. Among service providers who have limited experience with diversity, one negative experience with a person with a disability who is a person of color, for example, may serve as justification for distrust or extreme caution in all future service delivery contacts with people of color.

- **Caste Structure Viewpoint: Maintaining the Social Structure of Society.** Service delivery models that result in poor outcomes for the persons served preserve the status quo. Institutional barriers and limited regard for race, low socioeconomic status, and gender result in limited choice and low mobility. The outcome is that persons with disabilities, including those from diverse cultural backgrounds, are maintained as a permanent underclass of "clients" of the service providing class.

- **Cultural Conflict Viewpoint: Blaming Cultural Differences.** Persons from various racial or low income groups are viewed as essentially different and culturally deprived. The service delivery system is set up to serve those with a narrow range of acceptable differences. Differences in values, religious practices, language, and race fall outside of this narrow range and are viewed as unmanageable complications.

The inability or unwillingness of the service system to equitably serve persons with disabilities from diverse racial or ethnic backgrounds also affects those who are poor, or who have religious or sexual orientation differences.

■ Stage 3: Common Sense "Systems Change"

A fundamental shift in the balance of power between persons with disabilities and service providers is occurring as providers begin to respond to each individual's expressed needs, desires, and preferences in relation to supports. Instead of uniform, regulated options offered by the service system, providers are working *with* persons with disabilities to create *personalized* options. This is in stark contrast to service delivery models that use a one-size-fits-all approach.

With a few exceptions, changing the balance of power between people wth disabilities and service providers begins with requiring that service providers actually get to know and understand each person they serve in the person's natural environment (e.g., family, friends, daily routine). To design and implement personalized support services that culturally diverse persons with disabilities and their families find useful, service providers and delivery models must incorporate culturally responsive strategies. Among the essential strategies are the following:

- Approach diverse persons with disabilities and their families with a positive, unbiased attitude.

- Seek to understand the person first, including lifestyle choices and the factors most affecting quality of life from the individual's perspective.

- Obtain needed resources to provide total access to communication, including use of preferred language of the person with disabilities and key persons within their informal support network.

- Create a personalized set of supports by working collaboratively with the person with disabilities, key persons within their informal network, and other agencies or services.

- Change agency level regulations and procedures that inhibit innovative service practices.

- Take steps to ensure that the service providers and service system reflect the diversity of persons with disabilities who are being served.

- Hold service providers accountable for consumer satisfaction and outcomes related to employment, independent living, and social activities of the diverse persons being served.

As new roles between service providers and persons with developmental disabilities are being negotiated, categories of differences such as race must be acknowledged and respected. The ability of a service provider to effectively serve an individual – the whole individual – rests solely on the provider's ability to understand and embrace the person's uniqueness. Beyond that, the ongoing challenge is to create and maintain an environment in which humane and gentle interaction with all our fellow global inhabitants will be the rule, rather than the exception.

Betty Horton is Assistant Research Professor with the Institute for Life Span Studies, University of Kansas, Lawrence, and also Director of Magnet Schools with the Topeka Public Schools, Topeka, Kansas. She may be reached at 913/233-0313, ext. 401.

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The Need to Reconfigure Our Hard Drives

by James L. Mason, Tracy Williams-Murphy, and Laura J. Brennan

It is estimated that one in six Americans has some type of disability, with over 40 million having a developmental disability. Given the diversity within this population, those providing services must be aware of the ways in which stereotypes and prejudices impact the attitudes and behavior of service providers. This article outlines several major historical shifts in the evolution of attitudes toward persons with disabilities, and a direction for future practice that will lead to services that build on the strengths and respect the diversity of children and adults with disabilities.

Throughout history, people with disabilities have been at risk, even in so-called advanced societies. They have endured numerous atrocities, often because of myth and superstition. Although overt forms of oppression such as infanticide and ostracism have subsided to some degree, the general societal view of persons with disabilities continues to be negative.

In early hunting and gathering societies, as well as many later societies, children and adults with disabilities were viewed as burdensome, based on the notion that people had to be ambulatory and physically able in order to contribute. This resulted in persons with visible disabilities being killed as a means of protecting scarce resources. Vestiges of this view remain with us today as reflected in our tendency to value more highly the "able bodied" and "productive."

The "burdensome" perspective gave way to the "charitable" view. This slightly more benign attitude led to societal pity, sympathy, and paternalism. Well-intended churches and philanthropies believed it was their duty to help the "deserving poor." Part of that assistance, based on the ideal of protecting vulnerable people from society, involved housing people with developmental disabilities in isolated settings called "colonies." In the early 1900s, this attitude mutated into the belief that society needed to be protected from the people with disabilities. This belief, known as the *Eugenics Scare*, was based on the perception that the gene pool would be ruined by persons with mental retardation who, it was believed, bred rampantly and indiscriminately. The solution was to house them for life in large, segregated institutions.

Hohenshil and Humes (1979) believe we are now in what could be labeled the "egalitarian era." Influenced by civil rights efforts to remove barriers for African Americans and other groups of color, disability advocates from the 1960s onward have lobbied to assure rights for persons with disabilities. But similar to the lessons learned by groups of color, the passing of legislation does not usually result in rapid changes in attitudes and behavior. Because there have been few positive images to balance out the negative images of persons with disabilities, society's hard drive is in serious need of reconfiguration. And when there are additional layers of negative stereotypes related to other characteristics of members of this diverse population – such as race, gender, class, religion, ethnicity, age, and sexual orientation – the process of changing attitudes and behaviors can seem overwhelming.

Because there have been few positive images to balance out the negative images of persons with disabilities, society's hard drive is in serious need of reconfiguration.

A positive response to diversity is *cultural competence*. In the reauthorized Developmental Disabilities Assistance and Bill of Rights Act of 1994, the term "culturally competent services" is defined as "...services, supports or other assistance that are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language and behaviors of individuals who are receiving services..." Cultural competence regards culture as a key component in the service delivery process. It holds that professionals and organizations need to value diversity, conduct cultural self-assessments, understand the dynamics of difference, have access to cultural knowledge, and adapt to diversity. Culturally competent agencies engage in a process that includes recruiting and managing a diverse workforce, identifying and removing barriers to effective service delivery, participating in community activities, and evaluating culturally-specific service outcomes. This approach also, at its best, incorporates the involvement of persons with disabilities and their families from diverse communities as collaborators in the provision of quality services. They are an under-utilized resource that can help evaluate service delivery, conduct community education, develop advocacy or legislative strategies, and participate in or inform research.

Ultimately, this combination of cultural competence and consumer involvement can help create person-centered services that respect and support the diversity that exists in the population of persons with disabilities. And that is the most promising era yet.

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Forging Coalitions

by John W. McClain and James E. Van Arsdall

Minority group members with disabilities are in a state of crisis. The social and emotional consequences of poverty generate chronic drug/alcohol abuse, low birth weight, premature births, AIDS, accidents, and violence, all of which have influenced the steady growth of a chronically disabled population (physically and mentally). The reality of chronic disability among minority group members is worsened by an often uncaring and/or insensitive constellation of educational, social service, and rehabilitation systems.

The problems of persons with disabilities from minority groups are perpetuated, in part, because of the lack of racial/ethnic diversity among advocates, professionals, and public policymakers in the field of disabilities. In addition, traditional civil rights organizations such as the NAACP, the National Urban League, and LaRaza have not given systematic attention to this growing but often less visible issue. Yet, the issue of disability is sadly interwoven with many key issues facing minorities (violence, crime and punishment, health care, drug abuse) in late twentieth century America. Strategies must be designed and launched that generate a greater awareness of the issues associated with race and disability, and their interrelationship with key social ills, among the leadership and staff of traditional civil rights organizations. From awareness will come commitment, coalitions with disability advocates, and action.

Meyer Rehabilitation Institute, in collaboration with the Urban League of Nebraska and Arc of Nebraska, has designed and implemented a series of strategies that will cultivate minority parents and self-advocates as leaders in community disability advocacy efforts. The 36-month project, which began in 1995, involves four National Urban League affiliates in Omaha, St. Louis, Wichita, and Minneapolis. In each community, independent living centers also play key community organization roles in collaboration with Arcs.

The broad goal of the project is to design, implement, and test a range of strategies that will integrate the issues of minorities with disabilities into the national agenda of traditional civil rights organizations. The strategies used to reach this goal include the following:

- **Training in disabilities for Urban League staff.** Thus far, a two-day workshop has been conducted in Omaha that addressed types of disabilities, social consequence associated with disability, generic community disability resources, the economic status of minority group members with disabilities, and disability rights issues.

- **Community surveys for identifying issues and potential community disability advocates.** All 114 National Urban League affiliates will be surveyed about knowledge of types of disabilities, social concerns related to disabilities, local disability advocacy organizations and initiatives, and local public disability agencies. The results will be used to design further community activities.

- **Placement of community disability advocates on community boards.** The Urban Leagues of Omaha and Minneapolis have established advisory groups that include disability advocates, and the same process is underway in Wichita and St. Louis. These community advisory boards will provide further data for the design of specific community plans.

- **Establishment of a computerized resource library in each Urban League affiliate.** The resource library, which is already in operation in Omaha and soon to be replicated in Minneapolis, is a computer-based collection of hundreds of resources for a broad spectrum of individuals with disabilities. To augment the capacity of Urban League affiliate staff to serve minority individuals with disabilities and their families, a resource library will be installed in each Urban League affiliate office in Wichita and St. Louis. The library's listings are being organized by League affiliate staff and the disability advocacy advisory groups, and will reflect culturally appropriate formats for presenting the information as determined by the Urban League affiliates.

Through the above strategies and others, the project seeks to increase the level of awareness among staff of traditional civil rights organizations regarding issues related to minority group status and disability, and to assist those staff to conduct community outreach, education, and support activities related to minorities with disabilities. It is hoped that by forging these coalitions, much-needed leadership can be developed within the minority community to improve the ability of the service system to be responsive to the needs of minorities with disabilities, and the ability of minority communities to include and support persons with disabilities.

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Finding Support in a New Land

by Dao Xiong

As the number of refugee families coming to the United States from Southeast Asia has increased in recent years, there has been a growing need for outreach services that better equip them to work with agencies and obtain appropriate services for their children with disabilities. PACER Center (Parent Advocacy Coalition for Educational Rights) in Minneapolis is helping to meet that need through its Southeast Asian Project.

PACER is a statewide nonprofit organization that serves families of children and adults who have physical, cognitive, learning, and emotional disabilities. It was established in 1977 and carries out its philosophy of parents helping parents through offering workshops, individual assistance, and written information. PACER's programs help parents become informed and effective representatives for their children in early childhood, school, and vocational settings.

I joined PACER as a parent advocate in 1992 to provide information and resources to Southeast Asian families. Before becoming a parent advocate, I had many painful years raising my daughter who has mild mental retardation. I failed to access information and resources offered by PACER and others because I had high hopes that one day she would become an intelligent child, ready to face a challenging life and succeed in school. As a result of that experience, I wanted to help other Southeast Asian parents become more informed and better prepared as advocates than I had been.

In my role as parent advocate, my first step toward reaching Southeast Asian families of children with disabilities has been to connect with community organizations as well as with families that I know. One way I reach out to parents is through brochures and fliers translated into their language, and through a Twin Cities television talk show broadcast for the Hmong community in the community's own language. The language barrier is a major obstacle that prevents families from accessing resources, so providing translated information to organizations and individuals has been very important.

I have found that the single most successful outreach strategy is the home visit. During the visit I have a personal chat with parents and other family members about their concerns, which often include refugee life, clan relationships, their child's disability, educational laws related to their child's schooling, and effective decision making that will result in a successful service plan that enables the child to reach his or her maximum potential.

PACER also offers parent training workshops and individual consultation that use a culturally appropriate approach to provide concise, accessible, step-by-step information for families. I offer parents helpful information about raising a child who has developed differently from others. I do not mention their child's disability directly, but instead speak to them about federal legislation such as the Individuals with Disabilities Education Act and the state special education rules so that parents know exactly what their rights and responsibilities are under the law. In addition, advocacy skills are developed and encouraged so that parents are in the position to oversee and monitor all services that meet the needs of their child. The more knowledge about their rights and the better the communication, the higher their spirits as they deal with their particular situation.

Inservice and consultation for professionals about cultural difference are also offered. Tension between parents and service providers is often unresolved. There is frequently no understanding of the parents' concerns on the part of the provider, and the parents often are unclear about what their child is to receive and what the provider can give. Sometimes parents talk about services available, and professionals talk about service funding, which results in a negative interaction. Other times, parents feel that they don't want to be viewed as draining services, so they fail to express their concerns. One of the most important keys to success for providers serving Southeast Asian families and others from varied backgrounds is training in cultural sensitivity.

The success of Southeast Asian families in receiving the services and supports to which their children with disabilities are entitled and which they desire and need depends much on their own ability to overcome educational and cultural conflicts, their acquisition of new beliefs and effective communication patterns, and, most of all, their ability to handle stress and cultural change. I have found that the parents' own level of education and their length of time in the United States have the greatest effect on their involvement in their child's education. Those who have little education expect to have little involvement. Their culturally-based belief about respect is an important factor when it comes to accessing services; many families believe that parents are parents, and professionals are the experts in education. This makes it harder for them to access and advocate for services. As time passes and they become more adapted to American culture and more informed about their rights and responsibilities in relation to their child's education, I believe they will come to see that they are the experts about their children. Professionals need to be sympathetic and sensitive to the fact that parents need time to recover their positive self-image, build their own strategies to make better decisions, and be a positive influence on their child's education.

Dao Xiong is the Southeast Asian Parent Advisor with PACER Center, Minneapolis, Minnesota. He may be reached at 612/827-2966.

Searching for Answers

When my daughter was born in 1980, she was very healthy, both physically and mentally. She weighed 7.8 pounds, a lovely superbaby. My wife had no complications during the pregnancy or birth, and my daughter returned home from the hospital with her mother after two days. She was breast-fed, which created an emotional conflict with her 18-month-old sister who was still breast feeding. However, my older daughter learned quickly that she was old enough and it was time to give it up.

In Hmong culture, which I am from, when a baby is born to a family, a spirit calling must be performed by the elders or someone else who knows how. This must be done by the third morning after the birth to let the baby's spirit or soul join itself with the new family. However, with my daughter this did not happen here because I was new in the United States, and my parents and other relatives were still in the refugee camp in Thailand. A letter of notification that a newborn was added to our family was sent to them so that they knew what to do. No matter how far apart we were, our family was still intact culturally.

When my daughter was eight months old, she changed dramatically. She had a cold followed by a fever that lasted for two days. Following that she lost her appetite, acted differently, and became easily agitated in interaction with her older sibling. I noticed the change and knew I had to do something, but I wasn't sure what because I knew no one who could give me a helping hand or culturally-based advice. I saw a doctor and sent letters back to my family in Thailand where shamans and herbal specialists were available. The medical evaluation gave me no answers; it was too early to determine what was happening. In the traditional healing, the shaman went into a trance and discerned that the baby's spirit didn't like the name that I had given her, and a new name was sent to us. In Hmong culture, if the name is not satisfying to the child's spirit, she will not be a healthy baby.

My daughter continued to see medical specialists. They suspected that one reason for her problems was that she was born in the physician's office after just a few contractions. This birth experience was our first in the new environment, and my wife was scared of giving birth attended by a male physician. She was very frustrated and anxious about the delivery procedure, but knew of no alternatives. This kept her quiet about her labor until she could bear it no longer. In our first child's delivery, my mother and other elder women attended her and her privacy was not interfered with. This is why most Hmong American women prefer a nurse aiding their delivery.

Although the cause of my daughter's developmental problems could not be found, I always suspected many things. In the medical area, my wife's vitamin supplements during her pregnancy, her prenatal care, my daughter's illness with the cold and fever, the milk when she was off the breast feeding, and her delivery were always concerns for me. From time to time I shared my feelings about this with many medical professionals, but none of these causes could be confirmed. Because of my cultural beliefs, I wondered what guilt we had taken on during our past life and what punishment we deserved in our present life, and who had put this guilt upon us. Was her spirit unhappy with the way we cared for her? The search continued in hope that one day a miracle would come and completely cure her. We were told by professionals that we were not alone in having this kind of painful experience, but this did not ease our feelings about wanting to have a strong, healthy, and high moral superbaby, which was what she looked like in her picture hanging on the wall.

We continued searching for the cure and a miracle did happen: She was walking at age three-and-a-half. That was a very happy moment for all of us, including the professionals around her and my parents and relatives back in Thailand. One painful feeling was gone but others were still there as problems continued with verbal communication, motor skills, and many unspecified conditions. We were more alert to the potential she could develop, but were absolutely dependent on the medical professionals. She started saying a few words when she was five years old, and has continued to develop through the years. One painful moment, but one we were also grateful for, was a talk with her physician about the results of an evaluation. She was identified as having an unknown encephalitis that had no cure. Her condition would depend much on the new scientific and medical research in the future. It broke our hearts completely to hear that, and my wife started crying. But, we appreciated the sincere and great work her physician had done, and we will always remember her help.

There are many things we would like to know that go

Searching, continued on page 26

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Family Support in Inner-City Atlanta

by Lesa Nitcy Hope and Mary Yoder

The Atlanta Alliance on Developmental Disabilities (AADD) Family Support Program started in 1969 as a Model Cities project. The original purpose was to bring people back to metropolitan Atlanta from institutions across the state or keep people from entering institutions. This remains an important foundation for the agency.

The program serves individuals with mental retardation and their families in Fulton County (Atlanta), Georgia. The people served are primarily African American, and virtually all live below the poverty level. Most of those served also have other challenges – a diagnosis of mental illness, physical disabilities, substance abuse problems, and HIV/AIDS. All work is outreach in nature – done in the home and community of the person served. Outreach Specialists have worked in some of the most difficult situations imaginable.

The guiding principles of the agency are the following:

- Approaches need to be personalized and people need to be served on their turf.
- Services need to be flexible – available when, where, and how it makes sense for those requesting support.
- Decision-making must be decentralized, made by direct service staff closest to the family.
- Services need to be to the entire family, not just the person with a disability.
- Staff should be selected for their qualities and characteristics, not just their credentials.
- The relationship between the support staff and the family is critical. All involved need time and support to get to really know one another.

Forty-three percent of those served are mothers who have mental retardation. Most of the Outreach Specialists are strong women who serve as role models for the young mothers. They help them get good pre- and post-natal care, and teach them how to care for their children. They teach everything from sterilizing bottles and putting on diapers to appropriate developmental activities. They work very flexible schedules so that they can be at the mother's home when it makes sense for teaching and support.

The neighborhoods that people live in are often places where poverty, drug activity, and violence are the norm. Ongoing trauma and stress impact the families who live there in profound ways. For example, one young woman who is used to hearing the sound of gunfire close at hand is very sensitive to loud sounds and is exhausted by trying to stay vigilant. She does not feel comfortable sleeping in a bed because it is too exposed. She chooses low couches away from windows to sleep. Gang activity is the source of much of the violence. Young men and women in the families served are being recruited and initiated into gang activities. This includes young people with disabilities. This has raised an interesting paradoxical dilemma. Inclusion, acceptance, and relationships are ideals we hold as important, and these are precisely the issues addressed by gangs. We are trying to support other opportunities for inclusion in these communities and are working with community leaders and experts in supporting individuals who have expressed an interest in leaving gangs. These individuals have communicated their fears that the stakes are high – including fearing for their lives and their families.

Two of the common health problems we deal with are HIV and depression. We are serving an increasing number of individuals with disabilities who are HIV-positive or who have been diagnosed with AIDS; we are supporting them in getting connected to community resources and treatment to deal with their illness. Because people's life circumstances are complicated and difficult, many suffer from depression. We have made efforts to get appropriate counseling, treatment, and medication support to help people deal with this, as well. Because depression can be so debilitating, unless it is addressed it is difficult to work on other issues in life.

A major part of the program is its intentional practices that help families maintain or regain self-sufficiency. Among the practices are parent training and support; assistance in getting substance abuse treatment; job training with ongoing support; matching with long- and short-term volunteers; teaching practical skills such as cooking, doing laundry, using public transportation; assisting people with budgets and money management; going to medical appointments with people; assisting people in locating housing; training and support around sexuality and safe sex; supporting valued social roles in the community for all members of the family, and connections to neighborhood and community resources, groups, associations, and members; and supporting artistic and spiritual expression. There is no time limit on services. Some families have been served for 15 years and longer. One of the real strengths of the agency is its commitment to being with people over time.

Because the territory and situations of individuals and families served are complex and intense, AADD has made a strong commitment to providing support to staff. Staff have cellular phones to use so that they are able to have immediate and ongoing contact with the office, police, hospitals, and so forth. Staff development activities are tailored to each staff person's interests and needs so that they have time to stay abreast of best practices. Retreats, celebrations, and team meetings are scheduled so that staff have time to share what is happening and support one another.

Many families have said that AADD has been a life-saver. They have learned practical skills, gotten jobs, kept their children or been able to get their children back, stayed out of institutions (including jail), and obtained adequate food and housing. When staff were asked, "What is the most important thing that you do?", their collective reply was, "Listening to what people want and giving people hope. Hope is a wonderful gift – helping families make room for hope is the most important thing we do." Families agree. For the people we serve, believing that the present and future can be better makes all the difference in the world.

Lesa Nitcy Hope is Manager of Family Support, and Mary Yoder is Associate Executive Director, with the Atlanta Alliance on Developmental Disabilities, Atlanta, Georgia. They may be reached at 404/622-5343.

Anything is Possible

Minnie arranged her cap on her head. "Dana, how do I look?" Dana smiled, "You look great – ready for work." They walked from her apartment down to the corner where the bus would pick them up. As the bus pulled up, Minnie reached into her change purse and pulled out a token. She looked to Dana for reassurance, and seeing a smile and nod, slipped the token into the slot. Dana stepped on, and repeated the ritual. On to Georgia State University, where Minnie was beginning work with the physical plant. Her job would be to keep the plaza and library area clean.

Over the next weeks, Dana coached Minnie on the job, working with Georgia State employees to make sure that Minnie had a system to support her when Dana left. Minnie's winning smile and determination to do a good job drew people to her.

At the beginning, Dana and Minnie worked as partners in her job search. Minnie had requested support in getting a job for years, from agencies including Vocational Rehabilitation and various sheltered workshops. She had been evaluated and told she was unemployable, but she persevered in asking for help. At age 50, Minnie Johnson got her first job. "I had to wait a long time, but I knew I could work. Someone finally listened."

There were so many things to learn – how to do time sheets, how to pack a lunch, how to wash and iron work clothes. Between Dana Nelson Lane, Employment Specialist, and Rena Tolbert, Outreach Specialist, all the different things that needed attention got it. They supported Minnie evenings and weekends, whenever and wherever needed. They worked on banking, using an alarm clock, and juggling life to get things done on weekends.

Minnie had also been requesting help in learning to read for years. Again, evaluations and professionals reported that they did not feel those efforts were worth considering. Minnie told Dana and coworkers about wanting to learn to write her name and read. Soon, she was enrolled in an Employee Assistance Program for literacy at Georgia State. Two days each week, on work time, she went to class. She learned to write her name and was then able to sign her time sheets.

Minnie and her husband were having some marital difficulties. Minnie asked Dana if she could help. Dana found out that Minnie and her husband could get marital counseling through her job. Dana also spent time discussing health, nutrition, and safe sex. They covered a wide variety of topics. All parts of a person's life are interrelated – you cannot separate a part from the whole.

"I used the tool of 'person-centered planning' to help me learn to listen to what Minnie wanted. She had dreams for the future and had tried for so long to get someone to listen to what she wanted. It is all about communication – she had the opportunity to speak, I had the opportunity to listen," Dana said. "It is amazing what is possible when you work together as partners."

Minnie made deep friendships on the job. Coworkers from other departments joined her for lunch. Minnie found using the alarm clock challenging, so a coworker said she would call her every morning to make sure she was up for work. The circle of her life and relationships widened, deepened.

As Dana would say, "It doesn't get any better than this. If you listen to what a person wants and then try to be creative in your support, anything is possible."

Contributed by Lesa Nitcy Hope in reverent memory of Dana Nelson Lane (in photo at left), who died on May 11, 1996, in the crash of Valujet 592.

Honoring Diversity Through Spirit and Faith

by Rev. Bill Gaventa

One of the significant paradoxes of the move to community inclusion, generic supports, and "holistic" care in relation to people with developmental disabilities is that service providers often overlook one of the major sources of personal and community support: a person's spirituality, religious faith, and congregational affiliation. A recent non-scientific survey on my part illustrated this. At the exhibit area of a statewide conference, most agencies had impressive exhibits outlining their services, with almost everyone listing psychological supports, socialization, and community integration or re-entry. I went around, listening and talking, and then asking, "So what do you do with spirituality?" No one could tell me. Later that day, 25 people came to a workshop on tapping congregational supports, half of them "consumers or families," all of them saying they did so because of the crucial importance that their faith or congregation played in their lives. None of them, in the two days of the conference, had heard other speakers address issues or possibilities related to faith.

Through the Congregational Supports Program of the University Affiliated Program of New Jersey (UAPNJ), a growing network of people, faith groups, service providers, and persons with disabilities are beginning to work together to assist people, congregations, and organizations in including spirituality, faith, and congregational supports in person-centered and family-centered supports. The program began in 1993 after I moved to New Jersey and began to work with the UAPNJ on ways to develop and support this kind of bridge-building work. It was a natural part of the UAP mission "to strengthen the capacity of communities to increase the participation of people with disabilities in all aspects of community life." Primary funding support for the program came from a Training Initiative Grant from the Administration on Developmental Disabilities, and from a grant by the New Jersey Developmental Disabilities Council to do a statewide congregational survey on inclusive ministries and congregational supports. We anticipate that future partial funding will come from collaboration between the UAPNJ and community providers to develop an accredited Clinical Pastoral Education Program to supervise and coordinate training of seminarians and clergy in community settings.

Addressing spiritual and congregational supports means using a variety of strategies that address the diversity of ways that spirituality is expressed or experienced by individuals, families, and professionals. Some of them are:

- **A statewide survey of congregations** to find out what congregations are already doing, tickle imaginations about the kinds of supports possible, and offer information on resources and contacts. The survey was distributed collaboratively through religious organizations, advocacy group newsletters, and county-based service providers. Our database now includes information from more than 450 congregations, and the initial summary report on the project is leading to a statewide coalition on inclusive ministries with representatives from all the above groups.
- **Training; through workshops and other events, at both the local and statewide level.** Most training events have also included resource displays simply to help people be aware of the quantity and quality of new resources and national efforts related to ministries with people with developmental disabilities and congregational supports. Training has also included working with agencies in the Building Community Supports project, primarily in central New Jersey, to develop field education opportunities for seminarians in New Jersey seminaries (Princeton, Drew, and New Brunswick theological seminaries). One agency, the Arc of Union County, developed that role into a part-time Community Chaplaincy position, filled by a recent seminary graduate who made a significant impact in helping consumers, families, and staff to become included in community congregations of their choice. Training modules developed for the Building Community Supports project have also included one titled, *Worshipping Together*, a module on strategies, skills, and resources for working with congregations and service providers that is part of a four-module curriculum.
- **Resources and technical assistance,** through developing a comprehensive (and traveling) library and collection of resources on congregational supports. Examples include forming a section on resources for congregational supports as part of the Building Community Supports Resource Kit, a guide to state-of-the-art materials on developing community supports. Another is the publication of *Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families: A Bibliography and Address Listing of Resources for Clergy, Laypersons, Families, and Service Providers*, a 60-page, interfaith resource listing.
- **Networking and consultation.** One of the values of the program has been the capacity of the UAPNJ to bring together people from diverse backgrounds, roles, and traditions around issues of faith, spirituality, and congregational supports. A prime purpose has been to help people learn from each other's stories and experiences about congregational inclusion and support of spirituality and faith. Our hope has been to facilitate the capacity of providers, families, consumers, clergy, and laity to work

together at a local level, illustrated in the formation of several interfaith task forces at county levels. That means fostering, from the outset, an attitude of respect for very diverse traditions, beliefs, and practices, while also exploring the universality of spiritual questions and dimensions in human experience such as, "Who am I?" (identity, tradition, culture, and faith); "Why am I?" (purpose, vocation, and contribution); and "Whose am I?" (belonging and inclusion). It also means helping congregations see their capacity for supports, helping providers recognize the variety of reasons people participate in congregations, and helping everyone support people with developmental disabilities by giving them opportunities to truly experience inclusion and support their own choices.

Strategies and values, as well as resources, say little about spirituality and faith until one talks about flesh-and-blood outcomes, and some of those have been truly exciting: a seminarian serving as a "church coach" for the inclusion and baptism of a young man living in a group home; a middle-aged man named Fred connecting with his Islamic faith community aided by Jesse, a Baptist minister working as a Building Community Supports trainee; a church calling an agency and saying "Thank you for letting ___ come to our church"; and a young man having a Bar Mitzvah after having his Jewish identity and that rite denied years earlier. These illustrate that families, consumers, and congregations are rediscovering old and new ways of hospitality and welcome, and the recognition that everyone has gifts to bring to communities of the people of God.

Rev. Bill Gaventa is Coordinator of the Community and Congregational Supports Program, University Affiliated Program of New Jersey, Robert Wood Johnson Medical School, University of Medicine and Dentistry of New Jersey, Piscataway; and Executive Secretary of the Religion Division, American Association on Mental Retardation. He may be reached at 908/235-4408.

Finding a Spiritual Family

My name is Fred Sultansade. I am 42 years old. I live in the East Orange Group Home. The most important things to me are money, my personal things, having a good time playing baseball and basketball, and going to the mosque to pray.

When my father was living he was Islamic. He was from Azerbaijan, on the Caspian Sea. I have pictures of him. My father read Arabic.

I used to live in another town. I used to dance with the girls there, exercise, and play checkers. I was thinking about Allah. I had a funny feeling I was going to go the mosque when I was there.

Now I live at the East Orange Group Home. When I first came here, I would listen to the "Nation of Islam" on the radio. Reverend Jesse helped me by finding a special mosque for me. Every time he'd be waiting right there for me. I go every Monday, Wednesday, and Frjday. If it's nice weather I always go to the mosque. I stay for 15 minutes, 30 minutes or 45 minutes. I listen to the English and Arabic version.

I like going to the mosque because I can express myself by saying, "Salam A'lechem, A'lechem Salam." I say blessings in Arabic. Reverend Jesse taught me how you have to do "wuudo" or cleansing (my father used to do that). He taught me I have to wash my hands, wash between my toes, on the left and right side, then you make prayers. I wear the white robe that Reverend Jesse bought me. When I go to the mosque, I say, "Salam A'lechem" to the other people and they say, "A'lechem Salam" to me. We talk to each other.

Reverend Jesse gave me a new name. My name is Mohammed Rasu. It means "great one." I was called Fridun when I was born. My dad was mad when I changed it to Fred. When I go to the mosque, people call me Mohammed Rasu. They are happy to see me.

I just want to pray for the whole wide world because I think it needs a prayer.

Contributed by Fred Sultansade (Mohammed Rasu), who lives in East Orange, New Jersey.

"Is It Okay for Me to Love?"

by Dave Hingsburger

"Is it okay for me to love?" This question, asked innocently 15 years ago by an individual served by York Behaviour Management Services, was difficult to answer. Though service systems had begun to recognize people with developmental disabilities as having a sexual drive, the idea of a drive towards relationships and intimacy terrified (and still terrifies) many service providers. While studies show that attitudes towards sexuality and disability are becoming more liberal in the area of sex education, attitudes become more restrictive when the focus is changed from the right to sex education to the right to relationships. And if the discussion moves from heterosexuality to homosexuality, attitudes shift sharply toward the negative. Even for those who seem to espouse an attitude of tolerance toward "homosexuals," there is often a lack of tolerance toward "homosexual relationships."

> It only seems obvious that if there are lesbian, gay, and bisexual people without disabilities, there must be lesbian, gay, and bisexual people with developmental disabilities.

Fifteen years ago, as behaviourists in an agency serving people with developmental disabilities, we had become used to calculations – to counting behaviours and graphing successes. The simple question, "Is it okay for me to love?" forced us to look at the heart and perhaps even the soul of a person with a disability.

Shortly after that question was first asked of us, we began our work in the area of sexuality, starting with a young gay man referred to us because of inappropriate sexual behaviour. Like any other agency, when faced with a referral for a behaviour "out of expertise" we referred elsewhere. The trouble was, there was no "elsewhere" willing to provide service. So, that young man forced us to re-evaluate and reaffirm our belief that all people with disabilities have a right to receive the services they need to live life, and carry on relationships, as they choose in the community. As a result, we established the York Behaviour Management Services Sexuality Clinic.

Clinical work in the area of sexuality has always meant working with the individual and the system. At the outset of our work in the area of sexuality, we believed that we needed to approach referrals for sexually inappropriate behaviours in the same way as other problem behaviours. It wasn't long before we learned that in order to extinguish inappropriate behaviours we had to work toward the possibility of appropriate behaviours. This is a simple concept regarding other challenging behaviours, but a difficult one for sexuality. We were faced with a dilemma: How could we put a person in a sex education program when they could be punished for using the appropriate sexual behaviours they learned? When the people we serve live in environments that punish sexual expression by persons with developmental disabilities, environments where sexual relationships between persons of the same sex are regarded as immoral, illegal, and/or perverted, how can we advise people to engage in behaviours that can lead to punishment, medication or expulsion?

In dealing with this ethical dilemma, we have come to believe that any person who advocates for sexual rights and expression for individuals with developmental disabilities also advocates for deep, profound, and earnest systemic change. A cornerstone of this change is the right to privacy. This right is taken for granted by many nondisabled people in North America, but has yet to be fully embraced by many agencies that support people with developmental disabilities. The right to privacy is integral to a life of dignity. In fictional books that depict totalitarian states, such as *1984* by Orwell, a primary feature of an oppressed people is the lack of privacy. We have learned that the first stone that needs to be anchored when building agency policies that support appropriate sexual behaviours and intimacy on the part of individuals with developmental disabilities is the right to privacy. The reason it's crucial is that without privacy there is no appropriate sexual behaviour. We have worked with a number of individuals who have learned that quick, furtive sexual encounters are safer than ongoing, intimate relationships. Many of those individuals have been punished by service providers for carrying on sexual relationships and have had their sexuality driven underground. The result is that they have engaged in sex that has been abusive, unsafe, and non-contextual. The simple fact that the doubling rate of the AIDS virus in the population of people with developmental disabilities is 22 months (the fastest rate in any group in society today) is a testimony to the failure of the developmental disability service system to support the individual privacy that promotes healthy sexuality, relationships, and attitudes. The AIDS virus grows best when it can feed off ignorance, fear, and hurry – the holy trinity of repression.

As we examined our response as clinicians and as an organization to the question, "Is it okay for me to love?", we set about changing our policies and doing staff and agency training related to sexuality. Working toward a well-trained staff, policy statements that encourage people with disabilities to live as loving people, and an atmosphere of welcome to all people with developmental disabilities has set the

Love, continued on page 26

A Witness to Courage

"Can we talk to you after the conference?" Public speakers hate this question. It means that someone wants us to sit and do a free consultation after we have spent an entire day in front of an audience. Few seem to realize that public speaking takes a lot of energy and at the end of a day all that is wanted is beer and bed.

Here my initial assessment was wrong. A small group of very nervous people gathered to ask me what I was doing the next day. They knew, they said, that I was staying over Saturday and flying home Sunday, and they wanted to take me somewhere. Right after presenting "pro-sex attitudes" in a state wherein agencies had an almost universally hostile practise towards sexuality and disability, they wanted me to get in a car with a bunch of them. I said that I was uncomfortable with the idea as they were all strangers to me and I could tell by their behaviour that something was up. They said they were just excited and really wanted me to come. To their credit they didn't pressure me, and just said, "We'll come by tomorrow morning at 10:00. If you decide then you don't want to come we will just drop it." I agreed.

The next morning I went outside the hotel to watch for them. When they drove up in a vehicle with an agency logo on it, I made my decision. I'd go. It seemed to me that it would take an awful lot of coordination to arrange for an agency car to abduct a harmless Canadian. I got in and we drove for almost an hour. I enjoyed chatting with them and I felt buoyed along by their excitement. We crossed a state line and I asked why we were leaving the state. They said, "Just wait."

We entered a smallish city and in moments were pulling into the parking lot of a Unitarian church. I went in with them and saw several people, many who had been at the conference the day before, rushing about decorating the sanctuary. Clearly I had come to a church where a wedding was about to be performed. I sat near the back with the group with whom I had travelled. When the music began the small crowd of about 50 hushed, an air of expectancy – no, reverence – filled the room. Then into the sanctuary, into the house of God, came a man with a developmental disability. He walked slowly, his gait that of one who had once worn the shackles of institutionalization. He looked to be near 60. I smiled, tears formed in my eyes. When I see people with disabilities marry, I recognize that the march to the altar to stand before God is long. They must march past societal bigotry, family disapproval, religious intolerance, and agency dictates. He finally reached the altar. The music stopped. Silence. The music began again.

From the other door came another man. He too was older. He too walked as if the chains that bound his feet had only recently vanished. I looked at the woman next to me and said, "What's going on!?!" She smiled and said, "They are finally getting married." She continued by telling me that they had met as young men in the state institution and had been caught together "engaging in sexual behaviours" (social worker for "making love"). They had endured years of punishment and separation. A staff member heard the story from one of the men and diligently set out to reunite them. When she found the other man living in a group home operated by the same agency in a different town, nothing could stop her. They would live together if they chose.

When they were reunited, they decided that they would not live together, they would not have sex, until they were married. They had been punished so often, told continuously that they were dirty, sinful, hateful creatures, that they needed to get married "like other people." When they were told that they couldn't get married, they cried but had seemed prepared for that answer. The staff member wouldn't let go of it. She visited a Unitarian church in their town and worked with the minister to find a church out of state where a ceremony could be performed. She felt that this would be far enough removed to protect the sanctity of the ceremony and provide the secrecy that was needed. Everyone there had pledged support and secrecy.

The two were informed that a marriage could be performed. The staff told them that while God might smile on the marriage, the government wouldn't. It would be a holy ceremony, not a legal contract. That was fine with them, they said, seemingly unconcerned that we in the modern world had switched allegiances and granted governments more power than God ever wanted.

"See the fellow on the right?" I nodded while noting the man who had walked in first. "When he was in the institution, he was castrated. They thought that would stop him from being homosexual and wanting to see his boyfriend. Can you believe it?" I can and did, having worked with two women with disabilities who had been clitorectomized to stop them from being sexual. How we hate the hearts of people with disabilities! We have caged their bodies, disfigured their genitals, drugged their thoughts. But we have never, ever captured their hearts or controlled their spirits. What other group of people could walk from institution hallways to community streets with so little difficulty? What other person could go from the sacrificial table of medicine to the altar of God and still take the hand of a man he had loved for decades?

The two men stood and pledged their lives to each other. They stood on holy ground and each professed, through their pledge, a faith in each other. Seeing the beauty and steadfastness of the human love and the power of the human spirit, I wept. And I believe, so did God.

Contributed by Dave Hingsburger.

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Empowering Families to Manage Services

by Marijo McBride

In the past, the management of services for people with developmental disabilities and their families was largely left to the professionals. Today, more and more consumers want to be involved in determining their own needs, desires, goals, and supports. There is growing recognition that each person with a developmental disability and his or her family are the true experts on their own situation.

Parent Case Management for People of Color (PCMPC) seeks to empower African American and American Indian parents, guardians, and individuals with developmental disabilities to participate more fully in the case management of services they receive. The program is committed to creating flexible training, technical assistance, support, and post-training follow-up that builds on the unique capacities of each family, and enhances their active participation in determining their own needs and directions. Through the program, participants develop knowledge and skills in the following areas:

- Case management procedures, responsibilities, and strategies.
- Civil rights of people with developmental disabilities.
- State-of-the-art service delivery and philosophy.
- Quality indicators in health care and other services.
- Effective use of resources.
- Maintenance of records.
- Procedures for effective meetings.
- Identification of needs, functional goals, services, and resources.

The PCMPC project is a collaborative effort of the Research and Training Center on Residential Services and Community Living at the University of Minnesota, and leaders in the African American and American Indian communities. Collaborators include Arc Hennepin (Minneapolis), Perspective Advocacy (a parent advocacy agency in Minneapolis), the Mille Lacs Band of Ojibwe Indians Human Services Division in rural northern Minnesota, the National Parent Network on Disabilities, and participants in the PCMPC. Since it began in 1993, the project has offered training, support, informational materials, and post-training follow-up to African American families in the St. Paul and Minneapolis metropolitan area, and has collaborated with the Mille Lacs Band of Ojibwe Indian Human Services Division to develop and implement training on parenting issues for human services staff, who in turn offer this training to parents they serve.

One of the cornerstones of the program is its respect for and responsiveness to cultural characteristics. Strategies for maintaining that responsiveness include the following:

- **Asking participants and collaborators how the PCMPC can be supportive.** This includes asking persons who could be affected by the program to assist in the development of the grant proposal; asking collaborators' advisory committees to review materials, training, and technical assistance; asking participants and collaborators what should be included in the training, supports, resource information, newsletter, and post-training follow-up; asking participants and collaborators where and when to meet or offer training, what refreshments to serve, and who should speak at the training; asking participants if, how, and with whom they would like to network; and asking and supporting participants and collaborators to be involved in all aspects of the PCMPC.
- **Creating a welcoming atmosphere by building on the information obtained by asking.** This has included considerations as simple as offering training and meetings for American Indians in locations where smoke detectors won't go off when the elders burn sage during blessings.
- **Communicating in order to build trust and acceptance.** An emphasis on building trusting communication is necessary to facilitate discussion of issues. The use of mentors and bridge builders between the PCMPC and other key agencies, participants, and communities has been essential in this process. The mentors have been crucial in giving direction when we, as project staff, didn't even know we were not being culturally sensitive. They have helped us understand when we didn't even know what we should know about diversity. The bridge builders are people who help others know about the PCMPC and connect the PCMPC to important issues, people, and agencies in their community.
- **Creating networking opportunities.** By networking with others, participants can support each other, share stories, and get ideas on how others have addressed similar concerns. During training sessions, PCMPC builds-in time for people to talk with and get to know each other. Participants are encouraged to connect with each other outside training sessions and this is facilitated by developing a phone list or other ways of connecting for those without phone access.

The PCMPC continues to build on the input of the participants and collaborators in offering training, support, information, and follow-up that are responsive to the needs

and wishes of the African American and American Indian communities served. In the coming year, the project will produce materials for distribution on a national level that will support others in implementing similar programs.

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Note: The PCMPC project is funded by grant #H133B30072 from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education.

A Journey of Understanding

I was asked to write this article because of a chance encounter at a United Way cultural diversity committee meeting. At that meeting, another person and I both wanted the last chocolate chip cookie. We decided to split it, and started to talk. We talked about our experiences and decided that we had a lot in common: kids the same age, professional lives that spanned many years, quick laughs, a love for the outdoors, a passion for righting wrongs, and a willingness to challenge the system. Because of our similar passions and interests we discussed collaborating on the development of a pilot project that would offer training to staff that support American Indian families who have members with disabilities.

Working on that project was a part of fulfilling my purpose on my journey as a pipe carrier. A number of years ago my son was kidnapped. In the midst of despair, I went to see some people of knowledge. They acknowledged my suffering and grief, and through them I became a pipe carrier for my people, pledging myself to help other women and children in hope that someone, somewhere, would also help and watch out for my son. Part of fulfilling that responsibility has been my work in helping families of children with disabilities to find the support and hope that they need on their journeys.

Over the course of two years, and with collaboration on the part of many people (including the PCMPC project), we developed a curriculum and offered training for American Indian families. Some of the things we learned from this collaboration – which involved American Indian and European American people – and what I am learning on my life journey, may be useful to others who are supporting persons with disabilities and their families. We found that in working across cultures it is important to:

- **Invite others to share in cultural experiences.** I invited a collaborator in the training to a traditional feast so that she could get to know people in the Mille Lacs Band of Ojibwe Indians. Part of the process of really getting to know the people was the opportunity to make fried bread for the feast. As we prepared the bread, we talked about the traditional meaning of preparing a meal as an act of giving back to the community and sharing in its life. She found this a new and refreshing contrast to her usual experience of "entertaining," which was typically very stressful and unrewarding.
- **Look at bridging the gap in understanding.** As we were developing the training, we looked at how we were taking notes and discovered that one person had the notepad facing horizontally and the other had it facing vertically. It was an eye opener: We can be different or use our tools differently, but still connect. The gap in understanding can be bridged by symbols, such as offering tobacco to the elders to show respect for them. We did this as we were developing the training, wanting our work to grow and benefit all families.
- **Lay a safe foundation to support others to think about questions they have.** Answer their questions in a way that continues the safe atmosphere for discussion. This is a way to grow in understanding of diversity. As a quote from Black Elk said: "To understand the thing or the act is to understand true meaning."
- **Share success stories so that others who may be struggling have hope no matter what their barriers and disadvantages.** Be willing to be a mentor for others so that you can go full circle in the empowerment process and your journey of understanding.

Contributed by Diana Larsen, a private consultant based in Brainerd, Minnesota, who works with families at risk. She may be reached at 218/828-8369.

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Seeing the Wheel Within the Wheel

by Earl Schwartz

Every human being's personal story is interwoven with the larger story of one's family and the community or communities in which one lives. Each of us is, as the prophet Ezekiel said, a wheel within a wheel, a personal story within the ongoing story of those who have preceded and will succeed us. Every human endeavor that seeks to move an individual, be it educational, political, social or therapeutic, is prospered by careful consideration of the relationship between an individual's story and the larger stories that may encompass it. For the past seven years, the Jewish Learning Hour has served as a setting for Jewish adults with developmental disabilities to explore this relationship.

The primary purpose of the Jewish Learning Hour is to enrich the lives of its participants through an ongoing encounter with Jewish life, lived in concentric circles of community. Four to eight participants meet monthly at the St. Paul (Minnesota) Jewish Community Center. Most sessions are 60-90 minutes long. On Jewish holidays and other special occasions, sessions are also held at a local synagogue or the Minneapolis Jewish Community Center. Learning Hour programs are centered on a set of formal educational themes that include the Jewish calendar, Jewish values, and Jewish history. A given session may include storytelling, a film, a service project, a demonstration of a traditional Jewish practice, or the teaching of Hebrew terms. Sessions always conclude with a snack and hearty conversation.

The Jewish Learning Hour is one of the services offered through Caring Connections, a program for Jewish adults with developmental disabilities operated jointly by Jewish Family and Children's Service of Minneapolis, the Jewish Community Center of Minneapolis, the Jewish Community Center of St. Paul, and Jewish Family Service of St. Paul. Caring Connections began in 1990 to address needs that were not being met within the county service delivery systems, primarily the need for social, recreational, and educational programs within a Jewish context. Its specific goals are to enhance the opportunities for Jewish adults with developmental disabilities to have social support and interaction within the Jewish community; to reduce the stigma of developmental disabilities in the Jewish community, facilitating the community's commitment to ongoing education and support for its members with developmental disabilities; and, through the collaboration of the four agencies, coordinate services within the Jewish community and with the broader social services system. The Jewish Learning Hour is part of the educational component of Caring Connections.

Participants in the Jewish Learning Hour come to it as a result of the cooperation of local group homes, residential schools, and social service agencies. Most arrive with some knowledge of their Jewish background, and many have ongoing contact with family members who are Jewishly observant or active in Jewish communal life. Some have had little contact with the Jewish community in recent years, but recall Jewish practices from their childhood. Others are unaware of their Jewish roots, and are attending as a result of a chaplain, social worker, or residential counselor's concern that they retain contact with the Jewish community.

The most powerful moments have come at the intersections between the small circle of the Learning Hour itself and the larger circle of Jewish communal life.

The Learning Hour is intended to help members to learn about Jewish life in ways that bridge the distance between their own unique stories and the story of the Jewish people. Thus, in addition to its formal educational curriculum, Learning Hour activities are also designed to provide opportunities for participating in the life of the larger Jewish community, including synagogue services and community center celebrations on the Sabbath and festivals. In the seven years since its inception, members of the Learning Hour have shared many joyful, difficult, and touching occasions with one another, but the most powerful moments have come at the intersections between the small circle of the Learning Hour itself and the larger circle of Jewish communal life. Such intersections include the time Learning Hour participants received a spontaneous invitation to join in a wedding ceremony taking place elsewhere in the synagogue and when they were given the honor during a particular holiday service (now repeated each year) of collectively opening the "ark" in which the Torah scrolls are kept. Following one such service, the rabbi approached a Learning Hour participant to offer his condolences on the death of her sister. The Learning Hour member was astounded that the rabbi was aware of her loss. In the midst of her personal grief, in the company of the congregation, and as a member of the larger community, the rabbi had indeed found her. In such moments of welcome and respect, the Learning Hour's overarching purpose is realized with the drawing together of individual stories to form the greater wheel of a living Jewish community.

Earl Schwartz is the founder and Program Coordinator of the Jewish Learning Hour. He is also a faculty member at the Talmud Torah of St. Paul and Hamline University in St. Paul, Minnesota. He may be reached at 612/645-3244. For further information about Caring Connections, call Jewish Family and Children's Service of Minneapolis at 612/546-0616.

Being Jewish: Manny's Story

I was raised as a Jewish person. My parents put me in an institution when I was a child, and it was while in the institution that I started going to Jewish events. Some people used to have Jewish services and a huge banquet of Jewish food on Friday nights. I used to go there every Friday night for three or four hours. Through that I met a Jewish family that lived in the community, and after I moved out of the institution they took me into their home. They took me to synagogue a lot and helped me learn to speak my language and took me to Jewish summer camp.

After I moved away from that town, being involved in Jewish things kind of faded away. Some people I used to live with, my group home parents, got me involved in the Christian church services. The Christian church services were confusing. There was a lot more reading involved than with the Jewish stuff. I was raised as a Jewish person, and I understood it real well when I was small because I used to go to synagogue. Being involved with regular [Christian] church services and stuff got me so tangled up I didn't know whether I was coming or going. I didn't understand the Christian church services, but I understood my own.

Three or four years ago I got connected with Earl Schwartz. I went to Jewish Family and Children's Service and they got me hooked up with a program called the Jewish Learning Hour. There we talk about the various holidays, like Shabbat, the seder, Yom Kippur, and Hanukkah. They tell us what the holidays mean and how to celebrate them. Like for Hanukkah, they talk about lighting a candle each day for the Hanukkah season for eight days: you light one for the first day, two for the second, three for the third, up to eight until you get all of them lit. The Hanukkah season is the most important holiday to me because everybody around me is celebrating holidays – the regular people plus the Jewish people are doing it. The Jewish people celebrate at the beginning of the month and the regular people at the end with Christmas.

My biggest part in the Jewish Learning Hour is just being there, being a good listener, understanding what's being said. We all get along, we all help each other, we're all there together to enjoy each other's company. I've met other people besides Earl through the Jewish Learning Hour. I know two people that come frequently, and some others. But, I don't see them outside of class, except Earl.

Earl has been real good to me and real important in connecting me back with the Jewish community. I go with him to Beth Jacob congregation for services maybe once a month. I plan that with Earl and he comes and gets me. If we plan it early enough, I can get a ride from Metro Mobility. I went to synagogue a few weeks ago for the morning just to learn more about my own faith and how people deal with their losses and grief – the way the Jewish people do it, not the way the regular people do it. I lost somebody not too long ago and it hurts me. I learned to let it go and move on, which is real hard for me. Without connecting with Earl that would have been real tough. Earl breaks up my months by seeing me. It's real important that Earl be involved with me – it's quadruple important. I feel more relaxed with Earl and he explains to me what's going on in the services. Let's say there's a book right in front of me and I'm trying to follow along, like in these Bible books, and there's things I've never seen or heard of: I can ask Earl what they mean.

I know how to speak a little bit of Hebrew; it's not as good as it should be. I'm trying to learn how to speak it. I've already asked someone at the Jewish Family Service to look into where I could learn it, and she's going to do that and contact me. I have a book, but I need more help.

I would like to go to other synagogues, too. Jewish people have a little less advantage than regular people do in going to synagogue. The regular people have more opportunities to go to their churches than the Jewish people do; there's more going on than for Jewish people. I feel kind of left out, kind of lost. If there's a way I could go to synagogue each and every week I'd feel more relaxed. But to do that there'd have to be something closer to me, that I can do without using Metro Mobility. It costs too much to use Metro Mobility; it's five bucks per trip to Beth Jacob and I don't have five bucks to throw away. There's another synagogue kind of close to me that I've heard good things about. But I don't know how to go about getting connected with it. I was thinking about asking Earl for help or my counselor. If the synagogues provided vans or something to pick up people at their homes that would make it really easy for me. Then I wouldn't have to pay for Metro Mobility and I could go more often.

Contributed by Manny Steinman, who lives in Minneapolis, Minnesota.

Making Inclusion a Reality

by Ella Gross

The Institute for Minority Development in Minneapolis was founded in the summer of 1993 by a group of community folks that wanted to create an agency to serve the needs of isolated African Americans with disabilities. The group was comprised of six individuals – a teacher, a parent of a child with a disability, a legal secretary, a social worker, a retired city manager, and an accountant – who organized and formed the non-profit social service agency.

Why start such an organization in the midst of budget cuts and economic uncertainty? The timing was right. The era of large institutions was ending. The human services system was restructuring services with a focus on enhancing and preserving families, and trying to keep as many individuals with disabilities as possible in their communities. The information on how well the developmental disability service system was serving minorities was dismal: African Americans were more likely than many other groups to be labeled with a developmental or emotional disability. The research on minorities with disabilities was scarce, with few longitudinal or case studies available on the coping and resilience of parents of color who have children with disabilities. Very little was known about how African American parents felt about the Children's Home Care (or TEFRA) option, the Medicaid Home and Community-Based Services (HCBS) waiver, inclusion, transition, or down-sizing. The shifting in the paradigm of service, plus the need for a different kind of relationship between the service system and people of color, meant that the time was ripe for a new organization that focused on services to the minority community and that trained individuals for jobs in the disability services industry.

> We take into consideration their culture because it matters. Their culture, family, hair, food, and skin are elements of themselves that have to be loved, developed, and strengthened.

The mission of the Institute is to elevate the status and resources of children and adults with disabilities by developing networks and services for families in their communities that provide for their needs in housing, health, employment, and leisure/recreation. This mission includes keeping families together, teaching individuals to gain full employment, and enabling them to live in their community. With a staff of 22 we serve 19 families through three major programs: Parent Leadership and Training, In-Home Support, and Training for Direct Service Employment.

The Parent Leadership and Training Program started with a grant from the Minnesota Governor's Council on Developmental Disabilities. The program uses the Partners in Policymaking model, training parents to take a leadership role in shaping public policy and obtaining the services they and their family members need. The program gives African Americans an opportunity to be involved in the disability rights movement and make a difference in their own access to educational, residential, and early childhood services.

The In-Home Support Program serves children and families in their homes through the Medicaid HCBS waiver program. For African American families who feel isolated and mistrust the service system, this program is a way to teach them how to train their child in the home with a skilled worker present. Training includes independent living skills for persons with disabilities and parent management of home care services.

The Training for Direct Service Employment program trains African Americans to work in the field of developmental disabilities. African Americans are under-represented in the ranks of professionals, and little or no training is taking place to encourage them to work as direct care workers or choose a career in developmental disabilities. Our program has trained over 40 workers and managers so far, and over 75% of them have found work in disability-related services and programs.

For the past 15 years I've had the opportunity to work in the disability services and disability rights areas. For the first 10 years, folks told me that African Americans want to keep their children with disabilities at home. They also said that African American kids with developmental disabilities end up in the criminal justice system. Parts of those stereotypes were true and parts were false. Many African American parents kept their children in the home, without needed services, because the parents did not know there were services available or did not trust the services. And yes, there is an overwhelming number of African American children in the juvenile justice system who have developmental disabilities. They are there because of years of neglect by the traditional service system, which has made assumptions about what African American parents wanted for their children. There have been years of neglect as a result of advocacy groups not

> We recognize the person's presence in the world and give them an opportunity to share their difference with the dignity ensured by our constitutional rights.

reaching out to this underserved population.

Our program is tailored to meet the needs of the African American individual. We take into consideration their culture because it matters. Their culture, family, hair, food, and skin are elements of themselves that have to be loved, developed, and strengthened. We recognize the person's presence in the world and give them an opportunity to share their difference with the dignity ensured by our constitutional rights. The Institute for Minority Development was a response to a need in the African American community – the need to be heard and to be included in a civil rights struggle that has to include every individual in this community if we are going to make dignity, choice, and inclusion a reality for all people with developmental disabilities

Ella Gross is Director of the Institute for Minority Development, Minneapolis, Minnesota. She may be reached at 612/824-1125.

Making the System Work

Ada Townsend came to Minnesota in 1973, along with her mother and 11 brothers and sisters. They came from Kansas City, Missouri, to make a better life for themselves. Her mother and father divorced shortly after their arrival and Ada worked hard to help her mother, who was employed as a housekeeper and was also raising her large family. This experience of difficult family times gave Ada the skills of persistence and perseverance to tackle an educational system that wanted to label her son without identifying the resources she would need to help support him in her home.

Ada had a son, William, in 1978. She was a single parent and worked hard to raise her son. She also sought to make their neighborhood better for everyone, including William, by working as a community organizer.

Ada began to have difficulties with the public school system when William was five years old. A teacher claimed that her son was restless and suicidal, and insisted that Ada take him for an assessment. She did so, and the doctor said William did have a sleeping problem, but refused to label him. Ada's life became a constant battle, with the school and teachers sending William home because of his behavior. In second grade, William missed all but 56 days of school due to suspensions. Social Services investigated, but never provided assistance. Ada took William out of the public school and sent him to a private Catholic school, where he did well in third, fourth, and fifth grades. When William returned to public school in sixth grade, the same confrontations began. No one explained to Ada what Willam's rights were and what services he needed. William was labeled as having Attention Deficit Hyperactivity Disorder, and Ada received no information on how to handle his behavior or where to go for services.

In 1993, Ada was one of the first parents who graduated from the Parent Leadership Training Program of the Institute for Minority Development. As a result of the training, she not only learned about William's rights and available services to meet his needs, but she was also equipped to become an advocate for systems change. She has testified before the Minnesota Legislative Committee on Special Education Services, sharing her experiences with the educational system. She has also founded her own non-profit organization, Wills Advocacy Resource, Inc., to help other parents who are fighting for appropriate services for their children.

Ada's story exemplifies the struggle of African American parents. She did not know what special education services were. She did not understand her child's disability. She did not know where to go when her son was constantly suspended from school because of his behavior. William did not get services until they were ordered by the court as a result of a truancy hearing caused by teachers suspending William for his behavior. Ada says that she understands that there are people who really care, and she wants to be one of them and help other parents access the services they need and exercise their rights to appropriate support.

Contributed by Ella Gross. Ada Townsend is the Director of Wills Advocacy Resource, Inc., in Minneapolis. She may be reached at 612/853-1275.

Serving Children and Families Who Are Homeless

by Tawara D. Taylor, Marisa Brown, and Diane Jacobstein

The Georgetown University Child Development Center (GUCDC) is a division of the Department of Pediatrics of the Georgetown University Medical Center. The GUCDC was established over three decades ago with a mission to improve the quality of life for children with, or at-risk for, special needs, as well as for adults with developmental disabilities and their families. The center provides an interdisciplinary approach to service, training, technical assistance, research, community outreach, and policy analysis at local, regional, national, and international levels. It is part of the national network of federally-designated University Affiliated Programs that provide an array of activities supporting the independence, productivity, and inclusion of people with disabilities and their families in all aspects of community life. The GUCDC is supported by funds from a variety of federal, state, local, and private sources.

> The primary purpose of Kidstart is to provide advocacy and developmental services for preschool-age children and their families who are homeless.

The GUCDC is located in the District of Columbia, where the magnitude of need of individuals with developmental disabilities ranks among the highest in the country. The District is home to some 600,000 residents, many of whom traditionally have been unserved or underserved. The District's poverty rate is 16.9%. Its overall infant mortality rate is worse than all 50 states and more than twice the national average. Teenage pregnancy is a major problem, with 17.2% of all births in the District to women under the age of 19 years. Low birth weight accounts for 15.3% of all live births and area hospitals report between 22-40% of infants delivered as prenatally exposed to drugs and other substances. Homelessness, child abuse and neglect, and community violence have a devastating impact on many of the District's children and families. In addition, the city legislature and government have been forced to make tough choices to significantly reduce or discontinue program funding, leading to fierce competition for scarce funds among many constituencies with equally compelling needs.

For these reasons, the GUCDC focuses a significant portion of its outreach efforts on meeting the needs of unserved or underserved individuals and groups in the District of Columbia. In 1990, the GUCDC conducted a campus-wide forum to explore the role that the university could play in addressing homelessness, which has a high rate of prevalence in the District. Through collaboration with a local pilot project that provided mental health services to families who were homeless, the GUCDC identified the need to assess the developmental status of young children residing in emergency shelter. The GUCDC implemented a faculty volunteer program that provided developmental screening for children birth to five years of age living with their families in shelters. This initial effort was the basis for the GUCDC's Homeless Initiative that has been or is currently funded by grants from the Hasbro Children's Foundation, Better Homes Fund, Fannie Mae Foundation, and Administration on Developmental Disabilities, U.S. Department of Health and Human Services. These combined resources have resulted in development of a family-centered, culturally competent, community-based model of service delivery that responds to the needs of District families with young children who are homeless.

The Homeless Initiative has revolved around two projects. The first, Kidstart, is a national project funded by the Better Homes Fund and Fannie Mae Foundation. It was developed in recognition of the fact that preschool age children who are homeless experience increased incidence of developmental and emotional problems. Moreover, nationally, services and supports are overwhelmingly geared toward the school-age child who is homeless. The primary purpose of Kidstart is to provide advocacy and developmental services for preschool-age children and their families who are homeless. Each of the 17 Kidstart projects nationwide is administered in response to local need.

> The Knock On Every Door project is built upon a university-community partnership of outreach to families of young children living in emergency shelter.

The GUCDC Kidstart project is located within a child care center, Bright Beginnings, that exclusively serves families who are homeless and their children ages two and one-half to five years. Project staff consist of a clinical psychologist and family services coordinator who provide developmental screening and service coordination to children and families. Consultation is provided to the teaching and administrative personnel to facilitate the inclusion of children with developmental delays and disabilities into all aspects of the child care program. Kidstart project staff provide supportive services to assist children and families with transition from child care to local public kindergarten programs.

The second project, Knock on Every Door, receives primary funding from the Hasbro Children's Foundation and provides developmental screening, assessment, service

coordination, and other supports to families who are homeless and have children birth to five years. The Knock On Every Door project is built upon a university-community partnership of outreach to families of young children living in emergency shelter. The Knock on Every Door team consists of a project coordinator, clinical psychologist, speech-language pathologist, occupational therapist, developmental pediatrician/geneticist, a parent coordinator for family advocacy, and a pediatric nurse practitioner (the latter two also function as service coordinators). The two projects share team members who, through this collective experience, have

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Langston's Story

Mrs. Inga Borum is the great aunt and guardian of a four-year-old boy named Langston who loves books and music. In addition to raising Langston, she has reared an adult daughter and over the years has taken in many children of relatives. Prior to becoming homeless she worked as a geriatric aide. After Mrs. Borum and Langston moved to emergency shelter, Langston received developmental screening and diagnostic assessment through the Knock On Every Door project. He was found to have global developmental delays and be at-risk for a significant developmental disability. He was subsequently referred to the Bright Beginnings child care center. Consultation was provided to Mrs. Borum and the teachers at Bright Beginnings by the Knock On Every Door speech and language pathologist to help them plan for appropriate activities and interventions. This resulted in measurable gains in Langston's level of developmental functioning over a 12-month period. Mrs. Borum also received consultation from the Kidstart team, which helped her with interventions to address Langston's behaviors. The team further assisted her to advocate for special education services when it was time for Langston to transition from early intervention to preschool special education services within the public school system. Unfortunately, the school system had not designated an appropriate placement for Langston when school began in the fall. The Kidstart team assisted Mrs. Borum with obtaining legal counsel, with whose help Langston eventually was placed in an appropriate preschool program. In reflecting on these experiences, Mrs. Borum says:

> I was in the Center City Hotel (an emergency shelter facility) when I met Georgetown's Knock On Every Door team. They was going around knocking on doors and saying, "Do you want your child screened?" I knew Langston was not talking well and I wanted to see what the problem was. He would repeat what you say instead of answer the question. He got tested by the Georgetown people. They say he was behind in speech and language. They helped me because I didn't know about the programs and services they have for children with speech delay. They helped me understand what I could do to help him. They referred him to Bright Beginnings.
>
> He used to hit and throw temper tantrums because he couldn't express himself because of the speech delay. After Georgetown worked with him, he improved very much. Along with Bright Beginnings, they taught him to express himself without hitting and falling out, which was great. Now he has progressed, he's maturing, and he talks better. He can hold a conversation.
>
> I see lots of kids in the shelter whose parents don't know they have a speech or language delay. Even three- and four-year-olds that you can't understand what they say. Parents don't know there's a problem. They really need to be checked. It's not only kids in shelter. I see a lot of parents getting frustrated saying, "Talk! Talk!" They don't understand that their kid might have a problem. They think the child is lazy and don't want to learn. Sometimes it's because of their skills. Now I know what to look for and I be telling the parent maybe he have a hearing problem or a delay or an attention problem and should be checked. A lot of younger parents don't take their kids to the clinic like they should. A lot of these things they could find out early.

Contributed by Inga Borum and Diane Jacobstein.

Improving Outreach to American Indians

by Priscilla Sanderson

The American Indian Rehabilitation Research and Training Center (AIRRTC) was established in 1983 to improve the quality of life for American Indians/Alaska Natives with disabilities through conducting research and training that: 1) results in culturally appropriate and responsive rehabilitation services; 2) facilitates American Indian access to services; and 3) increases the participation of American Indians in the design and delivery of rehabilitation services. The AIRRTC does not provide direct rehabilitation services to American Indians with disabilities. Instead, it trains providers of rehabilitation services.

The training is developed based on information from annual surveys of service providers about their needs in relation to improving services for American Indians with disabilities. Training to non-Indian providers usually focuses on strategies to use for outreach services to American Indian communities on and off Indian lands, while training for Indian providers is usually regarding effects of traumatic brain injury and planning for vocational rehabilitation.

In training for non-Indian providers, the following are presented as some of the outreach strategies to enable them to better serve American Indians:

- **Read about the American Indian cultures in your respective states,** as well as gather information that provides an overview of lifestyles, sovereignty, treaties, employment, housing, tribal structure, and so forth. Through reading and gathering information, providers can develop an appreciation of the diversity among the American Indian tribes.
- **Provide American Indian individuals with clear written and verbal information** about rehabilitation services both on and off reservations. Consult with a linguist or nearby university that has an American Indian program for assistance in writing the information in the native language or culturally relevant language.
- **Develop or obtain a resource list of American Indian organizations,** American Indian Centers, schools, social service agencies, tribal service providers, community health representatives, or tribal/Indian Health Services public health nurses. By visiting with those on the list or others who are American Indian, assistance can be found in developing an outreach plan.
- **Review the organization's written and unwritten policies** on outreach services to American Indian tribes to identify flaws that can be corrected. American Indian advisors can assist in recommending outreach strategies that meet their community needs. Some agencies have hired American Indian technicians to serve as liaisons, assist with recruitment of consumers, and assist in developing culturally relevant services. It may also be desirable to subcontract with American Indian tribes to set up satellite offices that are responsible for outreach services.
- **Attend American Indian events that are open to the public** such as pow-wows, Indian rodeos, fairs, and American Indian lectures. This facilitates visibility of providers interested in American Indians and helps the providers better understand American Indian pride.

In addition to providing training to service providers, the center conducts research. A research project focusing on the vocational rehabilitation of American Indian adolescents and adults with fetal alcohol syndrome/fetal alcohol effects (FAS/FAE) began in March, 1996. The purpose of the project is to determine what information and procedures are needed to enhance the ability of counselors to address the rehabilitation needs of American Indian adolescents and adults who have FAS/FAE. The term "counselor" is used to refer collectively to vocational rehabilitation counselors, independent living counselors, school counselors, school psychologists, developmental disability case managers, job coaches, and other rehabilitation professionals.

In all our work, we recognize the importance of fully attending to cultural diversity in rehabilitation services. Although American Indian people may represent less than one percent of the total population in this country, we have as much diversity as the remaining combined population (Hodgkinson, et al., 1990). There are 309 federally recognized tribes and 197 Alaska Native villages. There are over 250 different languages still spoken among Native People. To provide culturally appropriate services for American Indians, providers, researchers, and trainers must involve American Indian consumers in identifying needs and priorities, and in designing, conducting, and evaluating research, training, and services.

Priscilla Lansing Sanderson is Director of the AIRRTC, Institute for Human Development, Northern Arizona University, Flagstaff. For further information on the AIRRTC call Karen Lang-Ferrell at 520/523-4791.

Note: The AIRRTC is a University Affiliated Program and is funded by the National Institute on Disability and Rehabilitation Research and Office of Special Education and Rehabilitation Services, U.S. Department of Education.

Reference: Hodgkinson, H.L., Outz, J.H., & Obarakpor, A.M. (1990). *The demographics of American Indians: One percent of the people, fifty percent of the diversity.* Washington, D.C.: Institute for Educational Leadership, Inc./Center for Demographic Policy.

Resources

The following publications provide information that may be of use to readers. Please contact the publishers of each for information about costs and ordering. Portions of this list are adapted with permission from O'Connor, S. (n.d.). Multiculturalism and disability: A collection of resources. Syracuse, NY: Center on Human Policy.

- **Disability and Diversity: An Annotated Bibliography** (1990). By the Massachusetts Developmental Disabilities Council. A bibliography listing resources on topics including adoption, cultural competence, cultural values, family, and model programs. It also lists resources by 12 targeted ethnic groups. Available from the Massachusetts Developmental Disabilities Council, 600 Washington St., Boston, MA 02111 • 617/727-6374.

- **Issues in Culturally Competent Service Delivery: An Annotated Bibliography** (1990). By M.E. Rider and J.L. Mason. A bibliography offering broad annotations related to multicultural issues and disability, especially mental health, and culture-specific annotations related to African Americans, Asian American/Pacific Islanders, Hispanic/Latin Americans, and Native Americans. It annotates primarily journal articles that include theoretical perspectives and practical applications. Available from Research and Training Center on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, OR 97297-0751 • 503/725-4040.

- **Disability and People from Minority Backgrounds** (1991). By the Office of Special Education and Rehabilitative Services, U.S. Department of Education. An issue of *OSERS News in Print* concentrating solely on issues related to people of minority backgrounds. Among topics addressed are vocational rehabilitation and American Indians, issues related to migrant farm workers, and students with limited English proficiency who are also labelled as having a disability. Available from OSERS, U.S. Department of Education, Room 3129 Switzer Building, 330 C St. SW, Washington, D.C. 20202-2524 • 202/732-1723.

- **Beating the Odds: Stories of Multicultural Inclusive Aging in Kansas** (1996). By B.T. Horton and S. R. Schroeder. A collection of profiles of 11 older adults with disabilities who come from diverse cultural backgrounds. Their stories are characterized by perseverance and determination in overcoming multiple obstacles. Available from the University of Kansas Affiliated Program, Schiefelbusch Institute for Life Span Studies, University of Kansas, 1052 Robert Dole Center, Lawrence, KS 66045 • 913/864-4295.

- **Towards a Culturally Competent System of Care, Volume I** (1989). By T.L. Cross, B.J. Bazron, K.W. Dennis, and M.R. Issacs. **Towards a Culturally Competent System of Care, Volume II** (1991). By M.R. Isaacs and M.P. Benjamin. Volume I is a monograph focusing on effective services for minority children with severe emotional disturbance. It was developed to assist states and communities in addressing the appropriateness of care for children and adolescents labelled severely emotionally disturbed, specifically dealing with the concerns and needs of culturally and racially diverse groups. Volume II (authors strongly recommend reading Volume I first) describes values and principles of a culturally competent system of care. It looks at 11 programs and highlights the culturally competent aspects of each. Available from CASSP Technical Assistance Center, Georgetown University Child Development Center, 3800 Reservoir Road N.W., Washington, D.C. 20007 • 202/687-8635.

- **Community Living: A Multicultural Perspective** (1994). By R. Traustadottir, Z.M. Lutfiyya, and B. Shoultz. In *Challenges for a Service System in Transition: Ensuring Quality Community Experiences for Persons with Developmental Disabilities* by M.F. Hayden and B.H. Abery (Eds.). A book chapter examining how gender, class, and race influence people with disabilities, the services they receive, and public policy. Available from Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285-0624 • 800/638-3775.

- **Bridging the Gap: A National Directory of Services for Women and Girls with Disabilities** (1990). By The National Clearinghouse on Women and Girls with Disabilities. A national directory listing over 300 services and support groups for women and girls with disabilities. Listings cover a range of areas such as educational services and offices of disability services at universities; support groups and other self-help groups; government and non-government organizations focusing on or including women with disabilities; and generic services such as rape crisis centers. Available from Educational Equity Concepts, 114 E. 32nd St., New York, NY 10016 • 212/725-1803.

- **Staff Attitudes, Homosexuality and Developmental Disability: A Minority Within a Minority.** By D. Hingsburger. Examines the difference in staff attitudes toward heterosexual and homosexual behavior, and discusses the implications of these differences for individual rights. In the *Canadian Journal of Human Sexuality*, 2(1), Spring 1993.

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beyond these classifications. There are other voices, among them many in human services, who recognize that life experience is shaped by the labels each of us wears. And while acknowledging the impact and reality of cultural identity and the cultural communities of which we're members, some of these individuals view focusing on such differences as divisive and counterproductive to providing efficient, cohesive services. They recommend finding the common denominator among people and basing services on that.

We hold a third view. We believe that race, gender, ethnicity, sexual orientation, class, and so on deeply shape the experiences of each one of us in relation to how we view ourselves, and how we view and are viewed by others. Conversations about such deeply personal issues that play themselves out in each of our lives must be held within the service system if it is to be truly responsive to the whole person with developmental disabilities. We recognize that talking about these characteristics and their impact brings up deep emotions, and therefore it must be done with care: care not to reproduce cultural stereotypes about categorical groups of people, care not to brush over the injustice and pain that people have experienced, and with care in the true meaning of care, caring about and for each other.

■ The Dominant Culture

American society, while amazingly diverse in its makeup, has identifiable norms and values that are seen as "American." These norms and values shape service systems as well as all the other institutions in which we as individuals participate. They generate inequality for those who are non-male, non-white, non-heterosexual, disabled, and/or not middle or upper class.

The developmental disabilities service system is shaped by and reflects the dominant culture in its values, expectations about the people it serves, and behaviors toward its staff members and service recipients. For example, most agencies are still headed by white men (although white women are now moving into these leadership positions) and employ large numbers of white, middle class staff members, especially in middle management positions. As another example, the rules and regulations by which services are organized reflect the values of the dominant culture and are not simply value-neutral attempts to ensure quality. Within the larger culture, having a disability can overshadow other aspects of a person's identity; so, too, our disability service systems tend to assume that the needs and experiences of people receiving services are determined primarily by the type and severity of the disability.

Many of the concepts promoted within our field are value-laden. Individuality, productivity, integration or inclusion, self-determination, quality, and independence all have different meanings to different groups of people. A person or family who wants services but attaches different meanings to these concepts may experience significant problems. The problems may arise because the rules and the people carrying them out are unable to bend. It may be that we are unable to see that by expecting compliance with the system's ways and norms, we are disavowing the person's or family's expression of their own values and identity. People who don't fit our perceptions of "good client" may even be denied service, pressured to conform, punished or ignored because of characteristics related to their racial or ethnic backgrounds, sexual orientation, class, or religion.

One way in which members of a dominant group attempt to erase or avoid the conflict and guilt that arise out of values clashes is to assert that all that is needed is to believe that "we are all just people," that differences exist but can be easily accommodated without the system or group having to change in fundamental ways. Under this view, prejudice and discrimination are acknowledged as operating within the larger society, but do not need to be examined or uprooted internally because "we treat everyone as individuals." Possible consequences of this approach are unconscious pressure upon people to assimilate and drop the ways in which they differ from others, or attempts to reform the organization by making small changes such as teaching staff about cultural and ethnic differences.

This view fails to account for the power of the cultural processes at work within organizations and individuals. An example is the way in which sexual expression is controlled within developmental disability service systems; heterosexual expression is controlled or prohibited based on assumptions about disability, and homosexual expression is controlled based on heterosexist assumptions, including personal moral beliefs. Both types of control are often denied or glossed over as unimportant in the context of the lives of people supported by the system. Discomfort, distaste, fear, prejudice and many other negative emotions operate to maintain the controlling stance of the system, even when there are attempts to introduce sex education, sexuality policies, and the like. Similar observations can be made about how differences rooted in race, gender, religion, ethnicity, age, and class are treated by the service system.

■ Valuing Diversity

Organizations and individuals who provide high quality services to people with diverse cultural identities do exist. These people and organizations are working to become more culturally knowledgeable, introspective about their own approaches, creative in bending rules and long-standing practices, and able to learn from the people they serve. Many more are grappling with these issues.

A number of currently promoted concepts and practices may have cultural relevance for families and individuals who are not members of the dominant culture. Some examples are:

- Person-centered planning, a process by which those closest to a person plan together to attain that person's most desired future.
- Circles of support, through which people selected by a person or family meet regularly to identify and help obtain a desired future.
- Family-centered care or planning, in which the family's strengths and needs are emphasized over the needs of the service system.

However, as with concepts like quality, productivity, and independence, we must examine and test these concepts for cultural relevance. Do they really make sense in every culture, or with every group, individual, or family? Can they be modified to fit what feels comfortable to a given family or individual, based on their own cultural identities? Are they not, in some basic ways, processes that are uncommon in any but a disability-oriented culture – mechanisms that were designed to overcome the shortcomings of the traditional service system? As such, we must be very careful as we apply them across the board. They may not fit.

■ Embarking on the Journey

We in the service and support industry can view the challenges discussed here as a reason to undertake a transformative journey. A beginning point might be to do an internal assessment that examines the beliefs and assumptions held within an agency or program about these important aspects of identity. Agency staff, along with people with disabilities and their family members, could be asked questions like:

- What is the agency culture, and how well does it accommodate diversity?
- Does the agency see and support the strengths of the people it serves, including those having to do with their culture, race, religion, sexual orientation, gender, class, and so on? In what ways could more be done?
- Does the agency have a climate that respects, listens to, and promotes understanding of the people it serves? Do people feel safe enough to bring up practices that are not culturally sensitive?
- What social, recreational, educational, and in-home services support people to participate in their own cultural and religious communities? What others are needed?
- Has the agency worked to respect the traditions people grew up with? Has it reconnected people with traditions they have lost?
- Are the agency's employees, management, and governing/advisory boards representative of the communities it serves?
- What steps have been taken to understand how illness and disability are perceived within the cultures of people the agency serves?
- Do the agency staff members know people who are involved in community and civil rights organizations? What could be done to build strong bridges to these community leaders?
- What are the agency's policies about sexual orientation? Is love between two people of the same or different sexes respected and supported by the agency? What else could be done in this regard?

We can use the results of such an assessment to identify steps we can take to begin on this journey, or to continue on it if we have already begun. Agencies and programs that do well in some areas but face challenges in others could ask families and people with disabilities to help them where they are most in need of change. Every agency can:

- Provide supports for each member's learning about cultural and other differences through training.
- Pair people who are different so that each can have direct experience of the other's traditions and ways.
- Guide staff in exploration of different ways of doing things.
- Record and "institutionalize" learning from what has worked.
- Encourage the sharing of stories during staff meetings, through newsletters, and in other ways.
- Create safe space for members to discuss issues arising from encounters with difference and to advocate for changes that would better accommodate diversity.
- Give permission for creativity and flexibility.

By examining our personal and agency assumptions and beliefs, by facing those areas in which we feel particularly threatened by differences, and by working to unlearn destructive or insensitive attitudes and practices, we can push past the discomfort zone and work together to generate a climate that encourages the people we serve to be openly and wholly who they are.

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beyond the description medical professionals have made of our daughter. I want to know what sources of therapy might be helpful to increase her strength in motor development; how much her functional and social skills will develop; and most of all, the level of academic functioning that I can expect as her best achievement in school. However, it is understood that professionals do not want to go beyond what they have concluded. But, it would be very helpful if they would provide more information.

My daughter's disability has affected my family many ways. For instance, it limits my expectations about her educational performance; I feel that one's success does depend on one's capacity to be in a life-long learning process. She will encounter prejudice because of her race and her disability, and she must be capable of resisting and handling them, and may not be. As my children are becoming acculturated, there may be a change in the traditional expectation that children will maintain their close ties to the family and be ready to assist family members during a crisis. I wonder what that will mean for our daughter. Our choice of discipline is also more or less restricted by her ability to manage her own behavior. However, all of this has also created an endurance and strength in my wife and myself as parents that others may not necessarily develop.

Today, I have better knowledge about services and where to get information and assistance. I remember in earlier years talking to educators about her educational plan and related services, and failing to ask about all possible referrals to other support services. Occupational and physical therapy provided by the school were not explained in ways that I could understand that they would increase her muscle strength and promote better motor skills. Sometimes I was denied other services and information that would have enhanced my ability to monitor services she received. Other times, I felt that the information about services that was available was not delivered in a way that I could grasp.

Although there were many resources, my ability to capably handle my child's services came through the experience I had with PACER Center in Minneapolis. Through them I learned about my rights and responsibilities under the law, and worked with other parents whom I felt were better prepared to tackle service plans for their child and to work with professionals; they have helped me become more comfortable working with professionals. However, I still face many obstacles, and one of the most challenging is the cultural change. As I raise my daughter and my other six children in an environment that differs from that in which I grew up, I recognize the importance of voicing my opinions in public. Being assertive in the American sense was not something that I learned in my culture. Respectful behavior as defined by Hmong culture is different and was ingrained in me from childhood. It is still very valuable, but it might not be a good tool in seeking concrete, tangible ways to meet my daughter's needs. It is this kind of cultural adjustment that makes it even more difficult for Southeast Asian parents to find the assistance they need in helping their children who have disabilities. It is very important for all professionals working with parents from Southeast Asia to recognize this and adjust their strategies for working with us.

Contributed by Dao Xiong, Southeast Asian Parent Advisor with PACER Center, Minneapolis, Minnesota. He may be reached at 612/827-2966.

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stage for teaching people with developmental disabilities about relationships, responsibilities, and rights. Our clinic has offered a variety of services over the past few years to all people with developmental disabilities, including those who are gay, lesbian or bisexual. We have provided gay peer counselling, arranged for gay people with disabilities to meet with religious personnel from gay-friendly churches, and facilitated anonymous AIDS testing. With the cooperation of agencies now accepting of the full range of the human experience within the population of people with disabilities, travel and accommodations have been arranged for gay lovers to be able to date and form relationships. And people have been assisted in finding lovers lost to them through the process of deinstitutionalization.

"Is it okay for me to love?" This question could as easily be asked by a lesbian, gay or bisexual person without a disability. The acceptance of loving relationships between same-gendered people has yet to reach a level of societal tolerance. When the question is asked by a man or woman with a developmental disability it takes on another dimension. The position of our clinic has been that people who have developmental disabilities do not love any differently than people in the general population. It only seems obvious that if there are lesbian, gay, and bisexual people without disabilities, there must be lesbian, gay, and bisexual people with developmental disabilities. Advocacy for sexuality rights must therefore include advocacy for people with developmental disabilities who are lesbian, gay, or bisexual. This means advocating for the inclusion of sexual orientation into sex education curricula as a separate unit, not attached to disease or abuse. This means advocating for references to same-sex relationships in agency policies. And this means training staff that their opinions and biases are left at the door when dealing with people who love in ways unique to their spirits.

"Is it okay for me to love?" Sorry it took us so long to get back to you on that one, but *yes*.

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gained unique insight and expertise in the provision of services, supports, and advocacy to young children and families who are homeless.

The GUCDC is committed to the development and implementation of programs that utilize a collaborative community approach, and which are interdisciplinary, accessible, family-centered, and culturally competent. These values and principles guided the GUCDC in the development of the two programs described. The following describe the GUCDC's approach to implementing these values and principles within the context of the Homeless Initiative:

- **Interdisciplinary.** An interdisciplinary approach is integral to the delivery of comprehensive services for children and families living in vulnerable environments. The interdisciplinary team members cited above have the capability to address the broad range of needs among this population.

- **Accessible.** To insure accessibility, all services are delivered in community settings including child care centers, emergency shelters, temporary/transitional housing units, and a city-wide intake facility. General information is written in simple formats. Developmental screening and diagnostic reports avoid the use of jargon and are orally reviewed with families to ensure accessibility of information for parents who are illiterate or low-literate.

- **Family Centered.** Families who are homeless often come from backgrounds that include foster care, substance abuse, domestic violence, inadequate health care, and poor education. These factors influence what constitutes family-centered practices for service delivery. For most families, becoming aware that their child may have a developmental delay or disability that could permanently affect his or her life is a crisis situation. This factor added to other factors that have precipitated homelessness requires service providers to develop a sensitivity to complex family needs. Service coordination involves services for the child and extensive collaboration with other agencies to address the needs of the entire family.

- **Culturally Competent.** In order for service providers to be responsive to the needs of children and families from culturally diverse groups, they must demonstrate an understanding and acceptance of how illness, disease, and disability are perceived; the various help-seeking behaviors and attitudes toward health care service providers; preferences for traditional versus non-traditional approaches to health care and other services; and the family as the ultimate decision-maker for services and interventions for their families (Taylor, 1993). Project staff continue to acquire skills, areas of knowledge, and personal attributes that enable them to work effectively in cross-cultural situations, including an understanding of the major social and economic conditions affecting the particular cultural/ethnic groups served by this project.

These two projects combined have served over 500 children and their families during the past three years. Data from a recent sample of 150 children who received developmental screening from the Knock On Every Door project indicated that 60 children were found to have age-expected development, while 90 children were referred for further diagnostic assessment. There is a high rate of interest and compliance among families to receive diagnostic evaluations and other follow-up services. Project staff report only 10% of families refuse developmental screening or other services. The Kidstart program has been successful in helping 35 children with developmental delays and their families to access early intervention services or special education services, and with transition to kindergarten programs. Both programs have been effective in helping parents better understand how their children's development relates to parenting, particularly for children with special needs. They have assisted parents of children with disabilities to understand their rights in order to better advocate for needed services on behalf of themselves and their children. They have provided technical assistance to agencies serving the homeless population to build their capacity to respond to the unique needs of families of young children with developmental delays and disabilities. And through them the GUCDC has demonstrated a model to successfully influence local policy development and planning for the delivery of services and supports to families who are homeless. While this model has been implemented solely at the local level, it has demonstrated efficacy which merits replication in other communities and jurisdictions with a high incidence of homelessness across the nation.

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Reference: Taylor, T. (1993). *Partnerships to achieve cultural competence in research.* Unpublished paper presented at American Association of University Affiliated Programs Annual Meeting, Bethesda, MD.

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